THE CANADIAN CHRONIC DISEASE SURVEILLANCE SYSTEM

AN OVERVIEW

The Canadian Chronic Disease Surveillance System (CCDSS) is a collaborative network of provincial and territorial surveillance systems, supported by the Public Health Agency of Canada (PHAC). The CCDSS enhances the scope of data on chronic diseases in Canada and supports the planning of health resources and the development of health policies and programs. It collects data on all residents who are eligible for provincial or territorial health insurance and can generate national estimates and trends over time for over 20 chronic diseases (see the textbox **"Chronic diseases included in the CCDSS"**).[i]

CHRONIC DISEASES INCLUDED IN THE CCDSS

Cardiovascular diseases

- heart failure
- hypertension
- ischemic heart disease, including acute myocardial infarction
- stroke

Chronic respiratory diseases

- asthma
- chronic obstructive pulmonary disease

Mental illnesses

- mental illness
- mood and anxiety disorders
- schizophrenia

Diabetes

Musculoskeletal disorders

- osteoarthritis
- gout and crystal arthropathies
- rheumatoid arthritis
- juvenile idiopathic arthritis
- osteoporosis
- osteoporosis related fractures

Neurological conditions

- dementia, including Alzheimer's disease
- epilepsy
- multiple sclerosis
- parkinsonism, including Parkinson's disease

More information on these diseases is available at: www.canada.ca/en/public-health/services/chronic-diseases.html.

i In this document, the term 'chronic diseases' is also used to refer to chronic conditions, disorders, or health related consequences or events.

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WHAT ARE CCDSS DATA SOURCES?

To identify people with chronic diseases, provincial and territorial health insurance registry records are linked using a unique personal identifier to the corresponding physician billing claims, hospital discharge abstract records and prescription drug records.

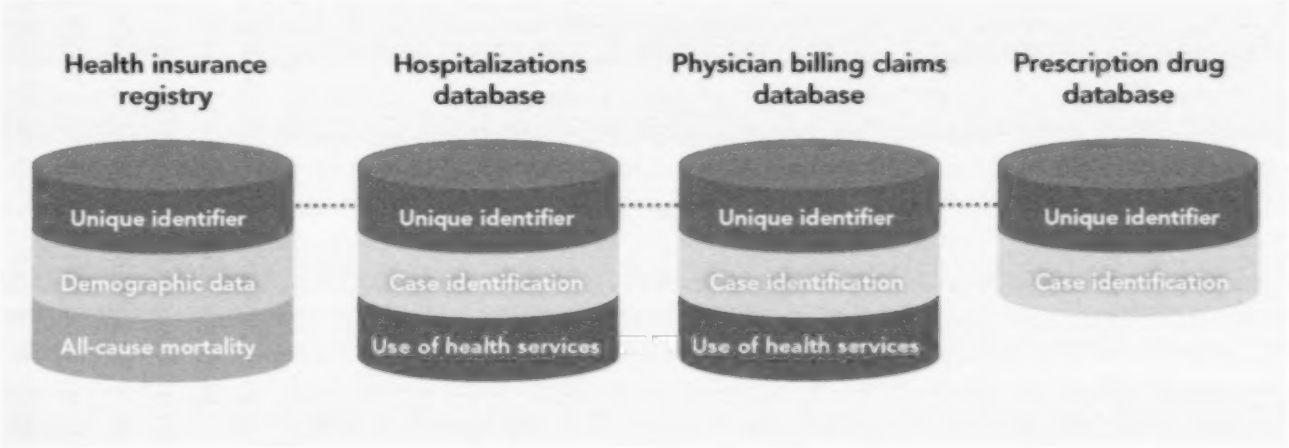
Data are collected by fiscal year since 1995–1996 in most provinces and territories.[ii] However, the start year for reporting CCDSS data is determined on a case-by-case basis for each disease to allow enough time to capture all prevalent cases as well as to ensure that previously prevalent cases are excluded from incident cases.

Under this distributed model, CCDSS data extraction is conducted in each jurisdiction using a standardized analytical protocol developed by PHAC.[1,2] Using this protocol, case definitions are applied to these linked databases and individual data are aggregated at the provincial or territorial level before being submitted to PHAC for analysis and reporting. Throughout the process, data are managed by the relevant authorities according to custodial obligations to protect patient privacy.

Each database (**Figure 1**) provides a specific piece of information contributing to case identification. The databases also provide additional health information such as:

- demographic data (age, sex, province or territory of residence);
- mortality data; and
- use of health care services (hospitalization, visit to a specialist, visit to a physician).

Figure 1. CCDSS data sources for case identification



ii Except in Quebec where the data collection starts in 1996–1997 and in Nunavut where data can only be reported as of 2005–2006.

Health insurance registry: The health insurance registry contains records for each person entitled to provincial or territorial health insurance.

Hospitalizations database: Provinces and territories record acute care hospital information using either the Discharge Abstract Database (DAD) or in Quebec, the "Maintenance et exploitation des données pour l'étude de la clientèle hospitalière" database (MED-ÉCHO). Hospital diagnoses are coded using the International Statistical Classification of Diseases and Related Health Problems (ICD).[3,4,5,6]

Physician billing claims database: Most physician activity in Canada is captured by physician billing claims,[7,8] either through fee-for-service or shadow billing claims,[iii] using ICD codes or diagnostic text, depending on the province or territory.

Prescription drug database: The comprehensiveness of the provincial or territorial prescription drug databases and their accessibility by the CCDSS partners vary across the country. For example in some provinces and territories, data are only available for the population aged 65 years and older. The drug dispensed is coded using a drug identification number (DIN) issued by Health Canada.[9] Currently, only the case definition for dementia, including Alzheimer's disease, uses this data source for reporting purposes.

WHAT ARE CCDSS CASE DEFINITIONS?

A CCDSS case definition (see the textbox **"CCDSS case definition using diabetes as an example"**) is a set of rules that enables the identification of cases of a disease in a given population. The majority of CCDSS case definitions are validated through comparison against clinical diagnoses. The list of case definitions and diagnostic codes used for conditions included in the CCDSS is available online.[10]

CCDSS case definitions are developed through a rigorous process, led by disease-specific working groups which are comprised of representatives from PHAC, provincial and territorial governments, epidemiologists and clinical experts. The development of a new case definition is comprised of four main steps, with examples of publications listed in the references: 1) literature review,[11] 2) validation studies,[12,13] 3) feasibility studies,[14,15] 4) and a national pilot.[16] The evidence generated throughout this process is carefully analyzed to select a case definition for the purposes of national surveillance.

CCDSS CASE DEFINITION USING DIABETES AS AN EXAMPLE

Canadians aged 1 year and older are identified as having diagnosed diabetes (type 1 or type 2 combined) if they have at least one hospitalization record or at least two physician claims in a two-year period with an ICD code for diabetes.

To exclude gestational diabetes cases, evidence from women aged 10–54 is removed 120 days preceding or 180 days following an hospitalization with a record containing selected pregnancy-related and obstetrical codes.

iii An administrative process whereby physicians remunerated via various alternative payment plans submit claims using provincial and territorial fee codes, even though they are reimbursed by other means of payment.

WHAT DO CCDSS DATA PROVIDE?

CCDSS data can be used to report national estimates and trends over time of:

- incidence and prevalence;[iv]
- all-cause mortality (death due to any cause);
- health care utilization, such as hospitalizations and physician visits; and
- multimorbidity and comorbidity.

Other estimates on economic costs of chronic diseases can be produced using the CCDSS data infrastructure, when additional databases are linked to the system.

CCDSS data can be stratified by:

- age group;
- sex;
- province or territory;
- year; and
- disease status.

WHERE TO FIND CCDSS DATA AND MORE SURVEILLANCE INFORMATION ON CHRONIC DISEASES?

- **Data tools, indicator frameworks, and data lab:** Public Health Infobase
- **CCDSS datasets:** Government of Canada – Open Data
- **PHAC reports, fact sheets, and infographics:** Canada.ca – Publications

iv. For mental illness and mood and anxiety disorders, annual use of health services is reported instead of prevalence.

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